



The California Alzheimer's Disease Task Force Final Report

1987

Task Force

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This report reflects the views, conclusions and recommendations of the Task Force only. It does not necessarily reflect the views of the California Department of Aging or any individual staff member of the Department.

**RECOMMENDATIONS TO MEET THE NEEDS OF
CALIFORNIANS WITH ALZHEIMER'S DISEASE AND
RELATED DEMENTIAS AND THEIR FAMILIES**

A Report to the Governor and Legislature

Prepared by the

California Alzheimer's Disease Task Force

1987

RECOMMENDATIONS TO MEET THE NEEDS OF CALIFORNIANS
WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS
AND THEIR FAMILIES

REPORT OF
THE CALIFORNIA ALZHEIMER'S DISEASE TASK FORCE

EXECUTIVE SUMMARY

In 1984, the Governor and Legislature approved the creation of an Alzheimer's Disease Task Force (Chapter 1599), which was to be responsible for advising State government regarding the program and service needs of Californians suffering from Alzheimer's disease and related dementias. The Task Force, working over a two-year period to gather data and expert opinion, held public meetings, seminars and symposia focused on special concerns, and, in May 1986, a statewide Conference on Alzheimer's Disease. As issues were raised at these public events, the Task Force commissioned scholars and experts around the country to write reports on specialized topics. This document is the culmination of this data gathering and represents the opinions of the people of California as reported to the Task Force.

Major Themes of This Report

Alzheimer's disease is characterized by unremitting, progressive mental and subsequent physical deterioration over a period of five to 20 years. Currently, the ultimate deterioration of capacities is inevitable and irreversible and results in death. There is no known cause or cure for Alzheimer's disease. Alzheimer's disease and related dementias already affect as many as 715,000 Californians and the cost of care may be as high as \$5.28 billion annually.

At present, California's health and social services system does not work on behalf of dementia patients and their families as well as it does for other diagnostic groups. Whether the diagnosis is heart disease, cancer, arthritis, stroke, or Alzheimer's disease, patients and their families should be covered equally by public and/or private systems of care and financing. However, this is not the case for Alzheimer's disease. Since patients with Alzheimer's disease and related dementias suffer gradual and progressive debilitation, their needs for care vary over the years of their illness--both in terms of the level of service they require at different times in their disease and in terms of how their needs compare with those of individuals suffering from other illnesses or disabilities. Patients with Alzheimer's disease and related dementias require a

"continuum of care" which allows for flexible service delivery so as to provide neither more nor less care than is needed.

The long-term care service system in California needs to be expanded and modified to address the needs of dementia patients and their families. Lacking the appropriate reforms, the existing system may simply perpetuate inefficient spending at the same time it fails to provide the services which could truly benefit patients. Where needed, a new system of care and services must be developed to respond to these needs. As part of this effort, those providers responsible for California's existing system of care and services for dementia patients and their families must be made aware of and become responsive to the needs of this population.

A significant number of dementia patients as well as families do not currently have access to existing services and programs. In particular, rural areas and other underserved areas are rarely able to provide any, much less all, the services needed by dementia patients and their families. Similarly, dementia patients without family members, as well as those who speak different languages or are of different cultural backgrounds, are at the mercy of public and private systems which are often ill-informed regarding the needs associated with dementia in general, much less the specialized needs of these populations.

It is also important to note that Alzheimer's disease and related dementias do not affect just patients. These diseases have an equally tragic impact on the families of patients as well. Thus, it is important to consider dementia as a disease of the patient and family. This report considers the patient and the family as a collective unit that needs support and assistance in coping with the disease.

Finally, the fight against Alzheimer's disease requires a multifaceted approach. It is just as important, if not more so, for California to support research in the area of Alzheimer's disease as it is to provide a comprehensive system of services and financing of care. Training and education for caregivers and professionals and changes in State law must also be implemented and expanded. This Report addresses the specific areas of concern identified by the people of California regarding: (1) Care, (2) Financing, (3) Legal Issues, (4) Training and Education, and (5) Research. Specific recommendations for each of these areas are presented in turn. The Report concludes with a recommendation for the implementation of an Alzheimer's disease program as a means of coordinating and improving California's efforts in combating Alzheimer's disease and related dementias.

CARE

The progressive nature of Alzheimer's disease results in a continuum of care needs which currently are not met by California's health and social services system. The demands of caring for dementia patients overwhelm family caregivers. Many needed services are either not available or not affordable. A disproportionate share of the costs of care for dementia patients falls on the patients' families. Existing law, regulations, and reimbursement policies discourage utilization of home and community-based programs for dementia patients and also may prevent institutional programs from offering appropriate services for dementia patients and their families. Patients and families often do not have access to services ranging from comprehensive diagnostic assessments to specialized institutional care. There is also a lack of evaluation research on which to base future program planning, development, and funding decisions in developing services for dementia patients and their families.

It is recommended that California's priorities for improving the care of dementia patients include the following:

- Making needed services more available and accessible. This should be accomplished by:
 1. Changing current law, regulations and reimbursement structures to make publicly funded programs more appropriate to the needs of dementia patients;
 2. ~~Expanding existing effective services.~~
 3. Eliminating disincentives for long-term care providers to develop new services; and
 4. Developing new services to meet critical needs of both patients and families, particularly such services as respite care and counseling for family members.
- Developing new licensure categories for long-term care programs providing specialized services to dementia patients. This should include appropriate reimbursement, staffing, activities and staff training requirements.
- Conducting a series of demonstration projects to encourage the development of a complete continuum of care to meet the unique needs of this population. Demonstration projects should be conducted in such areas as: respite care, specialized institutional programs, and counseling.
- Increasing funds designated specifically for reimbursement to specialized programs that take care of dementia patients with severe behavior problems.
- Conducting evaluations for all State-funded programs to serve dementia patients and families to assess cost-effectiveness and quality of care.

FINANCING

Nationally, the costs of caring for patients suffering from Alzheimer's disease and related dementias have been projected to range as high as \$48 billion annually. Conservatively assuming 11 percent, the California share is at least \$5.28 billion annually. At present, there are two meaningful sources of payment for long-term care services for dementia patients: private/personal resources and Medi-Cal/Medicare benefits for stays in skilled nursing facilities. Private insurance for dementia patients' long-term care is rarely available; furthermore, no private insurance plan provides sufficient coverage for the range of services needed. Current systems of financing care for Alzheimer's disease and related dementias rarely cover the costs incurred by patients and their caregiver families. Many patients and families are eventually impoverished as a consequence of the costs of formal and informal caregiving. Dementia patients are the most likely to require public assistance (Medi-Cal and Medicare) because of their age and because their personal resources are exhausted due to the extended duration of their disease.

It is recommended that California's priorities for improving the financing of care for dementia patients include the following:

- Expanding Medi-Cal coverage for services specifically required by dementia patients and their families, including diagnostic services; respite care; Alzheimer's disease day care; specialized residential, intermediate care, and skilled nursing facility care; hospice care; and autopsies.
- Obtaining a Medicaid waiver from the federal Department of Health and Human Services to permit Medi-Cal eligible individuals with dementia to receive in-home and community-based services.
- Developing incentives for the health insurance industry to create model long-term care insurance plans which specifically cover dementia patients for in-home, community-based, and institutional care (including respite care).
- ✓ Creating tax incentives for families to continue to care for dementia patients, particularly tax credits and tax deductions.
- Creating rate differentials or supplemented reimbursement for specialized care based on appropriate levels of care for dementia patients in in-home, community-based and institutional settings.
- Eliminating barriers in existing laws and regulations to the awarding of disability and pension benefits to individuals afflicted with dementia.
- ✓ Developing innovative sources of funding for dementia services and research.

LEGAL ISSUES

The inevitable mental deterioration caused by Alzheimer's disease and related dementias creates legal ambiguity regarding who should make decisions for patients who are mentally incompetent. Mental deterioration caused by dementia differs from loss of cognitive capacity caused by other diseases in that mental deterioration caused by Alzheimer's disease and related dementias is irreversible. An incident evolving out of a breakdown in judgment may be the initial trigger for clinical investigation of the disease and ultimate diagnosis of Alzheimer's disease. To the extent they continue to make their own financial and health care decisions, dementia patients may impose great emotional and financial burdens on their families. Therefore, the dominant legal concern for dementia patients and their families has to do with surrogate decision making. Having been designed to protect primarily the mentally ill or medically comatose, existing law fails to accommodate the unique circumstances imposed by progressive and irreversible dementia.

It is recommended that California's priorities for improving laws and regulations regarding dementia include the following:

- Amending current California law to provide for an "Irreversible Dementia Conservatorship" (IDC) to include but not be limited to the following powers:
 1. To authorize involuntary medical and health care treatment for an Alzheimer's disease or related dementia patient, including mental health treatment;
 2. To authorize involuntary placement of an Alzheimer's disease or related dementia patient in a locked facility or a secure environment; and
 3. To manage financial decisions and/or his or her estate.
- Identifying alternative mechanisms by which the request of a family member, health professional, or long-term care ombudsman would trigger review of the medical declaration that reversible causes of dementia had been ruled out with respect to any patient placed in a locked facility or secure environment or any patient on conservatorship.
- Amending State law to require county offices of the public guardian to provide conservatorship services for indigent dementia patients and to require the State to reimburse counties for the cost of providing these services.
- Amending current law to specify the order in which family members may assume decision making power on behalf of dementia patients.
- Eliminating the legal barriers to allowing division of assets for purposes of enabling Alzheimer's disease and related dementia patients to become eligible under Medi-Cal to receive in-home and community based services.

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TRAINING AND EDUCATION

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Current training and education for medical and allied-health professionals stresses acute care and provides only limited opportunities for students to gain experience in treating patients with chronic conditions, especially those in long-term care facilities. Training resources are particularly scarce in rural areas. Inadequate training for family caregivers can result in inadequate care for dementia patients or, even worse, in abuse. The public is poorly informed of the financial demands families may face in providing long-term care for dementia patients as well as the limitations on long-term care coverage available under Medicare and Medi-Cal.

It is recommended that California's priorities for expanding and improving excellence in training and education regarding dementia include the following:

- Providing funding to enable California's schools of medicine, dentistry, law, social work, nursing, psychology, gerontology, and other related professions to develop geriatric and dementia curriculum materials and giving schools and long-term care facilities incentives to participate in the upgrading of professional and para-professional training and education.
- Developing and staffing mobile diagnostic, treatment, and training units to serve dementia patients and their caregivers in rural and other underserved areas, which would also provide continuing clinical education in dementia for health-care professionals working in these areas.
- A.D.C.R.C. model* • Developing and implementing specialized training programs in dementia for volunteer care providers.
- Expanding efforts to disseminate personal, legal, financial, and social services information on dementia to the public, physicians, attorneys, programs for seniors and long-term care providers.
- Alb. Assoc. has done* • Establishing a 24-hour telephone information and referral service to provide service and program information for dementia patients and their caregivers.
- Establishing a dementia research clearinghouse in collaboration with federal efforts to disseminate to families and the public information regarding research on dementia.

RESEARCH

The annual costs of caring for Californians suffering from Alzheimer's disease and related dementias are estimated to be as high as \$5.28 billion. Little is presently known of the causes of these disorders, and there is neither a cure nor a treatment effective in preventing, arresting or reversing their progressively downhill course. Alzheimer's disease and related dementias affect approximately 715,000 Californians; the majority of these individuals are Alzheimer's disease patients. Unless means are found to prevent, treat and cure Alzheimer's disease, the burden will become overwhelming for the State. The answer lies in research, but the investment of federal dollars in this research is inadequate. Numerous problems, many of specific interest to California, are not addressed by federal programs. The scientific community, so well represented in California, has the tools, knowledge base, and means to solve the riddle of Alzheimer's disease. Although researchers are unraveling basic processes, the gaps in knowledge are still wide. The State can help accelerate the pace by furnishing resources to California's researchers. The State of California has the potential to solidify the pioneering role it has already charted and maintain its leadership in the fight against Alzheimer's disease and related dementias. A relatively small investment of State funds will bring rich returns both in knowledge and in research dollars flowing from federal and private resources.

It is recommended that California's priorities for continuing and improving excellence in research on dementia include the following:

- ✓ • Implementing a program of systematic investment in research on Alzheimer's disease and other dementias as a line item of the State budget. The goal for this annual State research allocation should be one percent (1%), but in no event less than three-tenths of one percent (0.3%) of the total cost of care for dementia patients in California.
- Supporting a broad spectrum of research on Alzheimer's disease and other dementias, which takes into account the multi-ethnic composition of the State of California and its unique physical, geographic and psychosocial setting.
- Designating the Health and Welfare Agency as the single State agency responsible for coordinating research on Alzheimer's disease and related dementias.
- Providing limited amounts of non-renewable initial funds to individual investigators in support of innovative projects on Alzheimer's disease and related dementias.
- Providing emergency or hardship funds to maintain the laboratories and research teams of established outstanding investigators in Alzheimer's disease and related dementias who have experienced substantial reductions in funding.

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PROPOSAL FOR AN ALZHEIMER'S DISEASE PROGRAM

During the past two years, the Task Force has listened to the people of California who have described the impact of the emotional and financial hardships dementia imposes on patients, families, and caregivers. It has become apparent that dementia patients and their families have particular health and social service needs which are not being met. In order to best meet the extensive and comprehensive needs of this population and those of the State, California must develop an ongoing, formalized capacity to implement and refine the recommendations in this report. Specifically, the State must continue searching for ways to improve California's existing system of health and social services to meet the needs of dementia patients along their own unique continuum of needs for care. All departments responsible for administering such programs must be required to respond to the needs of dementia patients and their families. California can meet these individuals' unique needs for care and support if the State will make an ongoing, well-coordinated effort that includes improving services, financing, laws, training and education, and research. Without such a concerted and high-level effort, California will fail to address adequately the needs of those individuals afflicted with Alzheimer's disease and related dementias or their families and caregivers.

It is recommended that California's priorities for establishing an Alzheimer's disease program for the benefit of persons with dementia and their families include the following:

- ✓ • Establishing an Alzheimer's Disease Public Advisory Committee (ADPAC) to serve as the mechanism to: (1) provide ongoing guidance to the administration and the Legislature; (2) review, in conjunction with an Interagency Coordination Team for Alzheimer's Disease, the implementation of Alzheimer's disease programs; and (3) encourage the collaboration of the public and private sectors in the development of Alzheimer's disease programs. The ADPAC is to be located and function within the Office of the Secretary of the Health and Welfare Agency.
- ✓ • Establishing an Interagency Coordination Team for Alzheimer's Disease (ICTAD) to ensure the implementation of the recommendations of this report in an efficient and timely manner. The ICTAD is to be located and function within the Office of the Secretary of the Health and Welfare Agency. In addition, an Alzheimer's Disease Program Coordinator is to be appointed in the Office of the Secretary of the Health and Welfare Agency.
- ✓ • Requesting the Secretary of Health and Welfare to report by no later than January 1, 1989, on the progress of implementing the Alzheimer's disease programs in California.

RECOMMENDATIONS TO MEET THE NEEDS OF CALIFORNIANS WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS AND THEIR FAMILIES

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ALZHEIMER'S DISEASE: OVERVIEW

- Alzheimer's disease is a disease which affects the brain causing progressive dementia and, ultimately, physical dysfunction as well. Numerous irreversible dementias are included in this category (e.g., multi-infarct, Parkinson's, Huntington's, Pick's, Creutzfeldt-Jakob, and AIDS dementia).
- As of now, persons afflicted with Alzheimer's disease can be neither cured nor rehabilitated. The course of the disease is one of unremitting, progressive mental and physical deterioration over five to 20 years, with death resulting usually from infection.
- Diagnosis of Alzheimer's disease is made by eliminating other known causes of cognition and memory impairments for which diagnostic techniques are available. There is no single reliable diagnostic test for Alzheimer's disease.
- In the U.S., Alzheimer's disease and related dementias afflict approximately 3 million individuals, most of whom are 65 years of age or older.
- Among the over-65 segment of the U.S. population, Alzheimer's disease is reported as the fourth most common cause of death.
- The incidence of Alzheimer's disease increases sharply with age: approximately 5 percent of the total over-65 population suffers from dementia; in the over-85 group, 20 percent or more are stricken.
- Survival rates of patients with Alzheimer's disease and related dementias have increased as large proportions of the over-65 population survive past 80.
- The Task Force has extrapolated from the U.S. Congress's Office of Technology Assessments' estimates that approximately 165,000 persons in California currently suffer from severe dementia, and an additional 550,000 have mild or moderate dementia. If present trends continue, the number of patients suffering all degrees of dementia in California will exceed 1,000,000 before the year 2020.
- From 40 to 60 percent of the U.S. nursing home population is afflicted with Alzheimer's disease or a related dementia. In California, this comes to approximately 45,000 to 67,000 residents in skilled nursing facilities alone.
- The costs of formal and informal care for dementia patients are extremely high. The average annual cost of nursing home care alone currently runs between \$20,000 and \$30,000 per person. The aggregate annual cost of care for dementia patients nationwide has been estimated to be as high as \$48 billion. The California share, conservatively assuming 11 percent, is \$5.28 billion.
- Most Alzheimer's disease patients are not being cared for in nursing homes but, instead, live at home and are attended by family caregivers. The services required by these patients--and their families and caregivers--range across a continuum of needs unique to the progressive deterioration caused by Alzheimer's disease. Specific needs for service vary from patient to patient and depend on numerous factors, including the illness which changes over time.

I. INTRODUCTION

Pursuant to Chapter 1599/Statutes of 1984 (AB 2733), the California Department of Aging (CDA) established an Alzheimer's Disease Task Force; the members were selected from the relevant professional disciplines specified in legislation (academic research, medicine, and mental health) and included three individuals representing families of persons suffering from Alzheimer's disease (Appendix A). The Task Force was assigned three specific responsibilities:

1. Provide guidance to the Department of Aging in the development of training programs and media resource packages;
2. Provide ongoing guidance to the administration and the Legislature as to the program needs of the Alzheimer's disease population; and
3. In conjunction with Department of Aging, convene a statewide conference to examine the state of the art, explore the progress of newly established programs and services, identify future needs for legislation and program development, and make recommendations on program needs.

In November 1985, the Alzheimer's Disease Task Force held five public meetings in the cities of Riverside, Ventura, Fresno, San Leandro, and Redding (Appendix B). From December 1985 through March 1986, the Task Force sponsored four symposia to invite professional caregivers, academicians, policymakers, and the interested public from California and throughout the nation to discuss their views on how to address the problems associated with Alzheimer's disease and related dementias (Appendix B). With data and information gathered at these hearings and symposia (Appendix C), the Task Force worked to produce a comprehensive picture of the problems encountered by Alzheimer's disease patients and their families and to recommend ways to mitigate these problems. With the Department of Aging, the Task Force convened a Statewide Alzheimer's Disease Conference in Sacramento in May 1986 to discuss policy options and strategies intended to ameliorate the ravages of Alzheimer's disease and related dementias.

The Task Force's findings and recommendations are presented in the next six chapters of this report: Care, Finance, Legal Issues, Training and Education, Research, and a Proposal for an Alzheimer's Disease Program.

II. CARE

Patients suffering from Alzheimer's disease and related dementing illnesses need care and services which are responsive to their particular disabilities. The long progression of mental and physical deterioration caused by Alzheimer's disease and related dementias produces a class of patients who require progressively more care. California's existing long-term care system fails to accommodate dementia patients' progressive needs. As a result, the financial, physical, and emotional burdens of caring for dementia patients fall on the patients' families--for those patients fortunate enough to have families who are willing and able to assume these burdens. Often lacking access to the kinds of community-based, supplemental services that could prolong family caregiving, many families seek relief by placing an Alzheimer's disease patient in a skilled nursing facility, intermediate care facility, or residential care facility, at which point much of the burden of care is shifted to the long-term care industry and the State.

The impact of poor care is felt at every level of society: by the dementia patient whose life has become impoverished; by family and caregivers who experience emotional, physical, and financial exhaustion; by service providers who experience frustration trying to provide quality care in inappropriately designed programs with inadequate funding and training; by the community where lack of appropriate care places a strain on existing services; and by taxpayers who are paying staggering sums for care which will continue to increase as our population ages.

Symptoms and Behaviors Common to Alzheimer's Disease and Related Dementias

In the early stages of Alzheimer's disease, patients experience memory loss, although they may try to deny this difficulty to themselves as well as others and may try to compensate for it. Apraxia (problems with carrying out purposeful movement) is a symptom of the disease which worsens as the dementia progresses. The same is true for aphasia (problems with language). Later on, the person afflicted with Alzheimer's disease will be unable to remember new information for even two or three minutes. Soon, patients cannot be left alone because of the danger that they may not comprehend their limitations nor the serious risk of accidents. At this point, the Alzheimer's disease patient may still be physically robust, which compounds the problem of managing inappropriate or aggressive behaviors. Dementia patients may not recognize their need for care and, thus, may resist help. For some, the apraxia progresses until they are unable to walk without help. Some become bedfast and need to be bathed, fed, dressed, and taken to the toilet. Behavioral problems eventually disappear due to the severity of the overall impairment. Seizures occasionally

occur. Artificial feeding may be required because patients refuse or are unable to eat.

In all stages of Alzheimer's disease, patients' behavioral excesses and deficits may cover a wide range. Unaware of their diminishing capacities, Alzheimer's disease patients often are difficult to control; logic and reasoning are ineffective in helping the patients to understand their affliction and how to adapt to it. Alzheimer's disease patients will cease to assume responsibility for household tasks they used to perform routinely. Gradually, such tasks as dressing appropriately, driving a car, paying bills, and other household tasks must be assumed by the primary caregiver. Persons with dementia may show angry outbursts, sudden shifts of mood, fearfulness, or violence. Dementia patients will require around-the-clock supervision and may often be awake and agitated at night, placing additional custodial stress on primary caregivers.

Alzheimer's disease patients cannot be rehabilitated. The course of the disease is one of unremitting, progressive mental and subsequent physical deterioration over an average of five to 20 years, with death resulting usually from superimposed infection. The decline in abilities can sometimes be postponed, and some disturbing symptoms can be treated but, currently, the ultimate deterioration of capacities is inevitable and irreversible.

The Cost of Care

Although dementing disorders represent the fourth leading cause of death in the United States--after heart disease, cancer, and stroke--the cost of care for dementia patients far exceeds that of other diseases. The following estimates of 1980 health care expenditures are taken from Losing a Million Minds, the report issued in April 1987 by the U.S. Congress's Office of Technology Assessment (OTA):

	Cost of Care (in billions)
Heart Disease	\$14.5
Cancer	13.1
Stroke	5.1
Alzheimer's Disease and Related Dementias	24-48.0

At the upper estimate of care costs for Alzheimer's disease and related dementias, caring for dementia patients would actually exceed the total cost of care for the other three diseases combined. In California, it is estimated that the total annual cost of care from both public and private sources, is approximately \$5.3 billion. Neither the national nor state cost of care estimate takes into account the

additional, unmeasured cost of the diminished quality of life many families experience as they drastically reorder their lives in an attempt to meet the long-term care needs imposed by the illness.

Care Issue #1: Persons afflicted with Alzheimer's disease and related dementias require specialized care over the long course of their disease. California's existing long-term care system does not accommodate this special need.

Alzheimer's disease and related dementias are not curable, but the lives of patients afflicted with these disorders can be managed in such a way that the course of mental and physical deterioration can be slowed. Most care for dementia patients is "social," or custodial: protecting patients from injuring themselves, protecting patients with behavioral excesses from damaging the environments in which they live (for example, starting fires or being involved in accidents), helping patients with daily activities they are no longer able to manage.

Therapeutic interventions have been developed to forestall the deterioration caused by Alzheimer's disease. The goal of the intervention strategies is to maintain optimal levels of functioning, despite the patient's underlying disease. Particular emphasis is placed on maintaining functioning that is only minimally impaired, such as allowing patients to dress themselves or prepare their own meals, thereby avoiding unnecessary dependency as long as possible. Therapeutic interventions seek to maintain as much patient activity and independence as is consistent with the patient's safety and the safety of others. This approach also includes appropriate medical treatment for acute medical disorders and emotional and behavioral symptoms.

New concepts in facility design, management, and staff training represent another category of therapeutic intervention. Special architectural designs and furnishing arrangements, for example, can minimize the confusion of disoriented patients and provide a safe environment. Specially-trained staff know how to deal appropriately with dementia patients' wandering, sleeplessness, agitation, and catastrophic reactions.

An appropriate system of care for Alzheimer's disease patients should offer the in-home and community-based support services which are required to make home care a viable option, as well as institutional facilities which are specially designed and staffed to provide care for dementia patients. California's existing system is characterized by an uneven distribution of resources needed by dementia patients and their families. The in-home and community-based services which dementia patients and their families typically find most beneficial are:

- Alzheimer's Disease Diagnostic and Treatment Services

Diagnosis of Alzheimer's disease is made through the exclusion of all other medical conditions. Ideally, the diagnostic assessment is conducted by a multidisciplinary team and results in the preparation of a comprehensive treatment plan. The Department of Health Services oversees six Alzheimer's Disease Diagnostic and Treatment Centers (ADDTCs) which provide diagnostic and treatment services for patients with dementing illnesses. ADDTCs offer specialized training in the diagnosis and treatment of dementia for health and social service professionals, as well as provide training and education to caregivers. They also conduct research studies into the causes, diagnosis, and treatment of dementing disorders. Existing centers need to be expanded and new centers must be developed in order to provide diagnostic and treatment services to more dementia patients and their families.

- Alzheimer's Disease Day Care

Alzheimer's disease day care is a group program designed to meet the unique needs of moderately to severely cognitively impaired adults. It is a structured, comprehensive program that provides a variety of social and supportive services to patients in a protected environment, thereby delaying excessive disability. In addition, day care provides respite time and social contact for caregivers. Day care for Alzheimer's disease patients is not currently a Medi-Cal benefit. The Department of Aging oversees eight Alzheimer's Day Care Resource Centers (ADCRCs) throughout California (the program will expand to establish eight additional centers during State fiscal year 1987-88). Existing centers need additional funding and new centers must be developed in order to provide specialized day care services to dementia patients and respite care to their families.

- In-Home and Out-of-Home Respite Care

Family caregivers often express the desire for an in-home respite care provider, or paid companion, who can come to the home a few hours each week to stay with a dementia patient while the caregiver attends to tasks other than care of the patient. Such aides should be trained to provide personal care (e.g., bathing, dressing, or feeding). Caregivers also need intermittent breaks from caregiving overnight, for several days, or even for several weeks. Families who are able to obtain such assistance often are willing to provide care for dementia patients at home for many years. Unfortunately, obtaining respite care for caregivers of dementia patients is nearly impossible. The Department of Mental Health oversees seven Regional Resource Centers (RRCs) throughout California which provide vouchers for respite care. Under the direction of the Statewide Resources Consultant (Family Survival Project for Brain-Impaired Adults, Inc.), the RRCs serve families and caregivers in multi-county areas. The vouchers for respite care available through RRCs do not nearly address the current demand for services. Five in-home respite care demonstrations and five respite care registry demonstrations have been established under the auspice of the Department of Aging. Six institutional-based respite demonstrations are to be established under the auspice of the Department of Health Services. All programs that provide respite care need to be expanded significantly to meet the demand for services that exists throughout the State.

- Residential Care

Residential care refers to any facility licensed by the State Department of Social Services to provide care and supervision in a family setting or group home for persons in need of personal assistance and supervision, but not nursing care. Residential care facilities serve primarily the elderly and mentally and developmentally disabled, but there is currently no special designation of facilities which have demonstrated a capacity to serve dementia patients. Residential facilities for dementia patients could provide a much needed alternative to existing institutional settings. However, residential facilities that lack specially trained staff and specially designed programs of activities for dementia patients may be an inferior alternative to nursing home care, depending on a given dementia patient's functional capacity and/or behavioral disorders.

- Adult Day Health Care and Adult Social Day Care

Both Adult Day Health Care centers (ADHC) and adult social day care centers currently serve dementia patients, primarily in the early stages of the disease. ADHC centers provide a day program of health, therapeutic, and social services in order to restore or maintain optimal capacity for self-care to frail elderly and impaired adults. Adult social day care programs provide social interaction and support services to elderly persons and functionally impaired adults who can benefit from day care but do not require the full range of services available in ADHC. ADHC is a Medi-Cal benefit while adult social day care is not. Current regulations require ADHC centers to provide costly medical and rehabilitation services which exceed the care needs of many dementia patients. Consequently, ADHC is not always appropriate for dementia patients. Moreover, current regulations do not require ADHC or adult day health care centers to provide staff who are trained to manage dementia patients' behavioral disorders, nor to provide programming to meet their unique needs.

- Individual and Family Counseling

Individual and family counseling, provided by trained counselors who understand the special problems of dementia and the family system, can reduce the emotional stress of prolonged caregiving. This need is largely unrecognized and public resources to provide this service are not readily available. Currently, the primary sources of State-supported counseling for families of dementia patients are the Regional Resource Centers and the Alzheimer's Disease Diagnostic and Treatment Centers.

- Legal and Financial Counseling

Caregivers, families, and patients frequently need information and guidance regarding immediate and long-term planning for financial and legal issues which occur as a result of the onset of dementia. This need is largely unrecognized and public resources to provide this service are not readily available. Currently, the primary source of State-supported legal and financial counseling for families of dementia patients is Regional Resource Centers.

- Support Groups

An important dimension of caring for a dementia patient is obtaining support and assistance for family members or other caregivers. When caregivers avail themselves of such support, they often find that it lowers stress. Formal and informal support groups organized by social service agencies, mental health agencies, non-profit organizations, and other groups can provide the opportunity for primary caregivers to give and take advice from each other.

- Eligibility Assistance

Administrative barriers to obtaining public assistance in caring for dementia patients very often derive from the fact that the primary caregiver is a family member. Assistance from individuals specially trained in entitlement law and regulations is often required in order to obtain services for dementia patients. This is especially true for minority groups with language barriers. Furthermore, dementia patients and caregivers in rural areas experience the additional burden of having administrative centers, particularly offices for reviews of eligibility, located in urban centers not readily accessible to them.

- Information and Referral

Information and referral (I&R) services link individuals having defined needs with information about programs established to meet those needs and referrals to specific agencies and individuals responsible for administering those programs. Because the services needed for dementia patients cover a broad range, caregivers often need assistance in locating and determining availability of services. Having to provide constant supervision of the dementia patient often prevents the caregiver from finding the time to get help that might greatly improve the patient's well-being as well as relieve the burden on the caregiver. Information and referral assists caregivers by shortening the process of obtaining whatever help may be available. Currently, programs such as Regional Resource Centers and Alzheimer's Disease Diagnostic and Treatment Centers provide information and referral services. In addition, the Statewide Resources Consultant and Regional Resource Centers provide a central clearinghouse function for providers and caregivers of dementia patients.

Care Issue #2: The demands of caring for dementia patients overwhelm family caregivers. Counseling and respite services often either are not available or are not affordable.

Dementia patients' caregivers usually are family members--most often a spouse, sibling, or child--who tend to feel sad, angry, and sometimes guilty over the patient's condition. Family caregivers often experience a deterioration in their own health; depression and other stress-related diseases occur frequently.

One of the most stressful series of decisions to be made is the first--that is, where the patient will be cared for, and who will provide the care. Dementia patients' families often find themselves designing their own health services plan for the care of their loved one. Thus, the family is forced to

absorb the stress of making decisions few families would feel qualified to make. Furthermore, deciding to keep a dementia patient at home means that the primary caregiver will confront an unprecedented degree of personal confinement. Nevertheless, in the overwhelming majority of cases involving dementia patients, nursing home placement occurs only after responsible family caregivers have endured prolonged, unrelenting strain (often for years), and no longer have the capacity to continue their caregiving efforts.

Caregivers often experience loss of sleep, loss of privacy, and loss of time for personal activities. In addition, caregivers frequently feel emotional distress over the patient's condition and withdraw from work or social activities due to the time involved in caring for the dementia patient. In some cases, counseling services can help families cope with these stresses (although counseling alone cannot solve the problems of inadequate care or limited financial resources). Not only can counseling serve as a therapeutic mechanism for relieving the stress of a caregiver, but it can also serve as a source of training to facilitate home care by helping the caregiver learn more effective strategies of managing the patient as well as giving the caregiver outlets for pent-up frustration.

Although many primary caregivers are middle-aged, some are elderly themselves, with chronic illnesses of their own, and may have difficulty meeting the physical demands of caregiving. More women than men are primary caregivers, partially as an extension of women's traditional roles, but also because most frequently a spouse becomes the primary caregiver and most wives are younger than their husbands. In cases in which a dementia patient is cared for by a sibling or child, the primary caregiver is again generally a woman.

The overwhelming need of caregivers caring for dementia patients in their homes is respite care. Although it can prevent breakdown in the family members' physical and mental health, the majority of in-home and community respite care services are not covered under public or most private health care financing plans. The ability of families to continue as caregivers--thereby preventing or delaying placement of dementia patients in institutions--may rest on the availability and affordability of this pivotal service. Without it, Alzheimer's disease and related dementias claim family members as victims. Provided caregiving does not become too stressful, home care is often in the patient's best interests. Patients tend to maintain higher functional levels longer while they remain in a familiar environment. When family disagreements over care decisions persist, however, or when family caregivers do not obtain the supportive services that could give them a break from the daily toil of caregiving, dementia patients may be better off in institutional settings which have been specially designed and staffed to meet their needs.

Care Issue #3: A disproportionate share of the costs of care for dementia patients falls on the patients' families.

Nearly all families of dementia patients report that their financial burden in providing care for the patient constitutes a hardship. Since care of dementia patients is long-term but often does not require medical treatment, even when the patient is institutionalized, such services as in-home respite care or day care usually are not reimbursed by public or private insurers. The financial burden of caring for the patient thus falls on the family, or another primary caregiver who assumes the responsibility, unless the dementia patient is placed in a skilled nursing facility or hospital where the cost of services may be at least partially covered by insurers, including Medicare and Medi-Cal. Due to the irreversible progression of Alzheimer's disease over a period of many years, the cumulative financial burden can be enormous. Frequently, in providing the 24-hour care that a dementia patient requires, the primary caregiver becomes the second victim of the disease. Often, if employed, the primary caregiver stops working in order to care for the person with dementia. Loss of income in such cases increases the financial strain on the family.

Care Issue #4: Existing law, regulations, and reimbursement discourage residential care facilities, intermediate care facilities and skilled nursing facilities from offering respite care services for dementia patients and their families.

The long-term care industry has been slow to respond to the special care needs of dementia patients. Providing services for dementia patients does require a number of costly preparations for which long-term care facilities currently receive no additional reimbursement. Thus, it is not surprising that long-term care facilities have hesitated to develop special services for dementia patients and their families. The existing long-term care system does not accommodate, for example, dementia patients' needs for short-term and repeated institutionalization. Day care and short stays in special skilled nursing units to help dementia patients through the more difficult phases of their disease would enable family members to provide care longer, delaying permanent institutionalization.

The lack of supplemental reimbursement to meet long-term care facilities' high costs is an obvious disincentive to the development and delivery of respite care for dementia patients and their families. The costs of staff time and administrative procedures associated with admission and discharge are not adequately reimbursed at the current daily rates to cover the costs of short-term placements. Furthermore, dementia patients require disproportionate amounts of staff time because they are often disoriented, agitated, may wander off, and are generally more difficult to care for when first moved to a new setting. Creating exclusive licensure and/or special units within long-term care facilities may be a good way of meeting the unique demands of caring for dementia patients.

Care Issue #5: Patients are often admitted to skilled nursing facilities with little documentation of having had complete diagnostic evaluations.

As frequently noted throughout this report, clinical diagnosis of Alzheimer's disease is made by excluding other known causes for cognitive and memory impairments. There are more than 60 reversible dementing conditions which resemble Alzheimer's disease. Therefore, complete diagnostic evaluations are necessary to prevent patients who need specific treatment interventions from being denied such services.

Current State regulations require that individuals admitted to skilled nursing facilities (SNFs) or intermediate care facilities (ICFs) (1) be admitted under the care of a physician, (2) be given a physical examination within 72 hours of admission, and (3) be admitted with a diagnosis. Current regulations do not require, however, that each patient's chart be reviewed upon admission to assure that there is medical support for the diagnosis. Because there is currently about a 20 percent error rate in the diagnosis of Alzheimer's disease, the lack of a requirement to review medical support for a diagnosis of Alzheimer's disease in particular may be producing inappropriate placements in SNFs.

Care Issue #6: Dementia patients who could appropriately be cared for in less restrictive settings are sometimes kept in state hospitals or circulate through the acute care system due to lack of funding in the mental health system to provide special programming and trained staff in institutional, community, or home-care settings.

Prior to the mid- to late-1960s, patients who required specialized care due to organic brain impairments were sent to state hospitals, thus becoming the responsibility of the State mental health system for ongoing care. Efforts to reduce the number of patients in state hospitals have resulted in shifting the primary care of many dementia patients to skilled nursing facilities.

Dementia patients are often hard to place, however, because many SNFs lack adequate staff for the management of severe behavioral disorders. Secured geriatric facilities, "gero-psychiatric" skilled nursing facilities, and State hospital beds are extremely limited, generally have very long waiting lists, and often are not located in the same community where the patients' families live. Furthermore, mental health consultation regarding techniques for managing difficult behaviors is a service which would expand the availability of care without requiring the establishment of new facilities. Although the mental health system can provide funds to those SNFs prepared to provide additional programming and special staff needed to care for patients with behavioral problems, the amount of money annually spent for this purpose is inadequate to meet the need.

Care Issue #7: State government in California lacks evaluation research on which to base future program planning, development, and funding decisions.

Few programs established to serve Alzheimer's disease and related dementia patients are being evaluated to determine their capacity to provide high quality services that meet the unique needs of dementia patients and their families in a cost-effective manner. Evaluation research is necessary in order to ensure that public funds for dementia patient programs are used for their intended purposes. In addition to assessing quality of care and cost-effectiveness, programs should be evaluated to determine the extent to which they meet the needs of: (1) culturally diverse groups, including those with language barriers; (2) dementia patients and their families in rural and other underserved areas; and (3) dementia patients without family members to assist them.

Recommendations

A. The Governor and Legislature should implement whatever changes are necessary in current law, regulations, and reimbursement structures to make publicly subsidized services appropriate to the care needs of dementia patients, and to make them readily available to dementia patients and their families. Making services readily available includes expansion of existing services as well as development of new services, including but not limited to the following (not in order of importance):

- Alzheimer's disease diagnostic and treatment services
- Alzheimer's disease day care
- In-home and out-of-home respite care
- Specialized residential care facilities
- Adult day health care and adult social day care
- Individual and family counseling
- Legal and financial counseling
- Support groups
- Eligibility assistance
- Information and referral
- Specialized programs in skilled nursing facilities/intermediate care facilities

The Governor and Legislature should also remove from current law, regulations, and reimbursement structures all eligibility barriers for dementia patients to receive services. Finally, all disincentives for institutional long-term care providers to develop new services specially designed to meet the unique needs of dementia patients and their families (including minorities and dementia patients in rural or other currently underserved areas) should be identified and eliminated.

B. The Secretary of Health and Welfare should establish new licensure categories for long-term care facilities--including Alzheimer's disease day care, residential care, intermediate care facilities, and skilled nursing facilities--which plan to design and provide services to dementia patients. This should specifically include provisions for reimbursement for specially trained staff to provide specialized services for dementia patients. Appropriate staffing and staff training requirements for such specially licensed facilities should be required.

C. The Secretary of Health and Welfare should implement a series of demonstration projects intended to encourage the development of a complete continuum of care having the capacity to meet the unique care needs of dementia patients and their families. The demonstration projects should include evaluation components for the purpose of comparing quality of care, staff training and qualification requirements, and cost-effectiveness in a variety of service delivery and service type alternatives. The demonstration projects should include, but not be limited to:

- Respite care, including short-stays in acute care hospitals or long-term care facilities, day care, night care, block time, and others
- Specialized dementia care within skilled nursing facilities/intermediate care facilities
- Vouchers for patient and/or family services
- Mobile diagnostic, treatment, and counseling units to reach rural and other underserved populations
- Counseling for dementia patients and their families
- "Volunteer credit" program for dementia respite care
- Hospice care for dementia patients in the final stages of their disease
- Regulatory reform to require a review of the diagnostic evaluation on every patient admitted to a skilled nursing facility with a diagnosis of Alzheimer's disease
- The role of nurse practitioners in skilled nursing facilities to improve the care of dementia patients

D. The Governor and Legislature should approve an increase in the budgets of the appropriate State departments to provide for supplemental reimbursement to community-based and institutional programs willing and able to provide the appropriate programming and specially trained staff needed to care for dementia patients with severe behavioral disorders.

E. The Governor and Legislature should require all programs designed to serve dementia patients to institute evaluation procedures intended to assess quality of care and cost-effectiveness. The Secretary of Health and Welfare should develop such evaluation research protocols in consultation with the proposed Alzheimer's Disease Public Advisory Committee.

OSHPD

III. FINANCING

Irreversible dementias are truly catastrophic long-term illnesses that alone cost this country tens of billions of dollars annually in health care expenditures. The financial drain on families of dementia patients is particularly severe. Nationally, the costs of Alzheimer's disease and other dementias have been projected to be as high as \$48 billion annually. The California share, conservatively assuming 11 percent, is as high as \$5.28 billion.

Dementia patients and their families pay for a significant portion of the costs of care for Alzheimer's disease out-of-pocket but, when necessary, may receive help from family, friends, or government sources. Current systems of financing care for Alzheimer's disease and related dementias rarely cover the costs incurred by patients and their caregiver families. Many patients and families are eventually impoverished as a consequence of the costs of formal and informal caregiving. Dementia patients are the most likely to require public assistance (Medi-Cal and Medicare) because of their age and because their personal resources are exhausted due to the extended duration of their disease.

Costs of caring for a person at home can become excessive through either direct payment for assistance in caregiving or through loss of personal or family income. Individuals afflicted with Alzheimer's disease and other dementias generally require counseling, personal care, and social services for many years. In addition to the medical cost of treating the symptoms of dementia, caregivers must also provide long-term supervision and assistance in activities of daily living, such as eating, bathing, and dressing. In fact, the cost of caring for a dementia patient also includes the costs of providing counseling and respite services for caregivers.

Dementia patients are likely to be institutionalized at some point during the course of their disease, at costs that average \$20,000 to \$30,000 per year in California. National studies reveal that two-thirds of individuals and one-third of couples aged 65 and older spend themselves into poverty within 13 weeks if they develop a chronic illness requiring placement in a skilled nursing facility (SNF). Individuals with dementia generally need skilled nursing facility care far beyond their capacity to pay for it, since the average duration for common forms of dementia is six to eight years.

At present, there are two primary systems for providing long-term care services: the informal system of family caregivers and the formal system of institutions. There are only two meaningful sources of payment for long-term care services: private-personal resources and Medicare/Medi-Cal benefits for stays in intermediate care and skilled nursing facilities. There is a significant absence of

private insurance to help patients and families pay for the costs of long-term care. While some public and private financing programs are designed to address the specific problems of financing care for dementia patients, none provides sufficient coverage for the range of services needed. For Alzheimer's disease patients who are 65 or older, Medicare pays for acute care services, including hospitalization, physicians, and laboratory services required for diagnosis and management of Alzheimer's disease. Medicare does not pay, however, for respite services, personal care, adult day care, adult day health care, or most skilled nursing facility care for dementia. Medi-Cal provides coverage primarily for nursing home care for impoverished patients, although some home and community-based services for all elderly patients are now covered under Medi-Cal. Most private health insurance mechanisms for financing care for dementia patients and their families exclude nursing home care and in-home and community-based care.

Financing the long-term care of dementia patients in California will be compounded by projections that the over-60 population in this State will increase by 70 percent over the two decades between 2000 and 2020. California's over-60 population is the largest in absolute numbers among all 50 states: 4.5 million. State census officials project that this age group will have grown to 5 million by the year 2000 and to 8.5 million by 2020: an increase of 70 percent in a period of 20 years. The demographics of aging portend significant increases in the cost of long-term care for Alzheimer's disease patients, because the incidence of Alzheimer's disease and other dementias is significantly higher among the elderly than among the general population.

As noted, financing long-term care for dementia patients is inadequate in 1987. As Alzheimer's disease and other dementias attack a rising percentage of the population, the costs of caring for these individuals will also rise proportionally. Unless a cure is found, we must begin now to devise ways of financing such costs. Otherwise the future holds two possible scenarios: either increasing numbers of dementia patients and their families will be impoverished, or the patients simply will not receive care.

Financing Issue #1: Public mechanisms for financing health care--specifically, Medicare and Medi-Cal--cover acute care and, when the patients become impoverished, nursing home care, but generally exclude in-home and community-based long-term and respite care for dementia patients and their families.

Publicly subsidized health care programs pay for acute care and rehabilitation services, but exclude long-term care except in intermediate care or skilled nursing facilities. A large percentage of dementia patients live in non-institutional settings. The direct testimony of caregivers indicates that

respite care is the most critically needed service for family caregivers of dementia patients. Neither Medicare nor Medi-Cal acknowledges the importance of the family caregiver's role in providing services to the dementia patient. Public mechanisms for funding health and social services for the elderly, including Medicare, Medi-Cal, Title XX (Social Services Block Grant), and programs funded under Title III of the Older Americans Act, provide minimal coverage, if any at all, for services supplied by family caregivers in the home or for community-based respite care to give family caregivers a break from the daily rigors of supervising and caring for a dementia patient.

Medi-Cal (Medicaid) has been the vehicle for California's public subsidy of health care since Congress amended the Social Security Act in 1965 to provide federal funds for this purpose. States have limited flexibility to determine eligibility and to specify covered services under the program. Over the past 20 years, California has added to the list of covered Medi-Cal services such categories as sub-acute care in skilled nursing facilities, adult day health care, and stays in intermediate care facilities (specifically for the developmentally disabled). The success of demonstration projects such as the multipurpose senior services program (MSSP) and Linkages have shown the importance of covering "social" services under Medi-Cal. To date, however, extended coverage under Medi-Cal specifically designed for dementia patients and their families, particularly respite care, is not available.

Financing Issue #2: Private mechanisms for financing the long-term care of dementia patients--to the extent such mechanisms exist at all--are inadequate to prevent the impoverishment of dementia patients and their families.

Private health care insurance is either inadequate, unavailable, or simply not structured to meet the chronic care needs of the dementia patient. Those dementia patients who have private insurance use it primarily to supplement Medicare. These private supplementary policies, however, rarely cover nursing home care, home health care, or social services. Although private insurance companies have begun offering long-term care insurance policies which cover some nursing home care, they usually limit the level of reimbursement and the length of coverage. Insurance companies are reluctant to offer long-term care insurance, because risk pools of the elderly make long-term care more certain than uncertain, minimizing if not eliminating the potential for profit. Thus, the marketing of long-term care insurance policies generally is targeted to those individuals who are younger, healthier, and have higher incomes. Even though Medicare does not cover the majority of nursing home care, elderly persons have not responded well to long-term care insurance programs. On the other hand, long-term care insurance policies do not offer the benefits most desired by patients and families anyway, and are often too expensive to be affordable by a large portion of the elderly population.

Catastrophic insurance currently means coverage for extremely large medical and hospital expenses associated with an accident or acute medical condition. Catastrophic insurance policies generally require a high deductible--starting at \$5,000 in any given year and going as high as \$25,000. Catastrophic insurance does not usually cover dementia patients, particularly not the cost of both medical and personal care.

Financing Issue #3: Federal and State tax laws provide weak incentives for families to continue as caregivers for dementia patients.

Current federal and State tax laws deny adequate credit for services provided in the home or by community-based programs. By allowing credits for purchase of services provided in skilled nursing facilities, however, the current tax structure works as an incentive to institutionalize dementia patients. On the other hand, although IRS regulations state that "medical care" includes the entire cost of institutional care for a person who is mentally ill and unsafe when left alone, institutionalization of a dementia patient to provide a safe environment may not be deductible.

Private resources for long-term care are quickly exhausted. By failing to acknowledge the financial sacrifices families make in order to provide long-term care at home, existing tax laws fail to maximize the purchasing power of family financial resources for long-term care. For example, families do not earn tax credits as a medical expense for the purchase of respite care or other services they require in order to remain in their caregiver role. Care expenses are tax deductible only when they are medically related, and most community-based and in-home expenses incurred in the care of dementia patients are regarded as non-medical.

One exception to the requirement that costs be medically related is the current dependent care tax credit, sometimes called the "child care tax credit," which is allowed for care of dependent adults as well as children. Twenty percent of expenses incurred in hiring someone to care for the dependent in order to allow the taxpayer to take a job are deductible up to a maximum of \$2,400 per year. Costs for day care also are included under the dependent care tax credit allowance.

The use of tax incentives as a resource for long-term care could provide an additional vehicle to assist families in financing care for their demented family member at home because these so-called "tax expenditures" are not subject to California's statutorily regulated ceiling on the State budget (the "Gann limit"), whereas direct expenditures of General Fund dollars are. The public policy goal is the same, regardless of how it is achieved: to reduce the financial burden on family caregivers to enable them to continue providing care for dementia patients at home.

Financing Issue #4: There are no special licensure or reimbursement categories for programs which serve dementia patients.

Restrictions in licensing and current reimbursement methodology preclude the delivery of specialized services to dementia patients in any substantive way in both institutions and community-based programs. This condition is the result of a lack of flexibility in licensing categories, restrictive reimbursement criteria, and a lack of research concerning the unique needs of the dementia patient. At present, there are several State demonstrations which, as part of their mandate, will recommend appropriate licensing categories for specialized services to dementia patients and their families. These include the Alzheimer's Day Care Resource Centers under the auspice of the Department of Aging and the Alzheimer's Disease Institutes under the auspice of the Office of Statewide Health Planning and Development. The Alzheimer's Disease Institutes will develop licensing requirements for a number of services for dementia patients and their families, ranging from in-home and community-based services to institutional care. However, there are no existing or proposed reimbursement categories for programs in California which serve dementia patients and their families.

Financing Issue #5: The lack of a funding source to cover the costs of comprehensive diagnostic evaluations prevents the timely development of conservatorships to assure that involuntary placement of dementia patients in a protective environment can be accomplished when necessary. In addition, the lack of adequate funding for autopsies precludes an accurate assessment of the number of dementia cases and definitive diagnoses for families.

Dementia patients are expected to reach a point of no longer being able to care for themselves or make meaningful decisions regarding their health care, financial affairs, or living situations. Any provisions for involuntary protective placement, however, particularly in locked facilities or secure environments, must afford due process protections for the proposed conservatee, including a comprehensive diagnostic assessment. Given the difficulty of correctly diagnosing Alzheimer's disease and other irreversible dementias, medical assurances that reversible causes of the dementia have been ruled out should be pursued whenever possible or appropriate. These assurances should be based on complete medical histories, complete functional assessments, and a battery of tests including a physical examination, neurological and psychiatric evaluations, mental status examination and psychometric tests, and appropriate laboratory tests. The cost of this battery of tests is often more than the patient or most caregiver families can afford. There is also a lack of public and private funds available for conducting autopsies, which is the only means of making a definitive diagnosis of Alzheimer's disease. Definitive diagnoses are important for researchers, public policymakers, providers, and of course, the families of patients.

Financing Issue #6: Disability and pension benefits for dementia patients often are either denied or delayed, owing to the long time required to make an accurate diagnosis.

People who become afflicted with Alzheimer's disease or a related dementia eventually become unable to work. However, many are not diagnosed as having dementia until years after their employment has been terminated. These individuals have great difficulty qualifying for disability benefits under Social Security, State, and private insurance programs. Although Alzheimer's disease patients may be unemployable at the time their employment is terminated, they may not appear disabled. The confusion created by the lack of a reliable diagnostic technique creates a financial hardship for Alzheimer's patients and their families, because employers and insurance companies contend that disability has to be substantiated at the time employment is terminated in order to qualify the employee for benefits.

Financing Issue #7: There are limited sources of public and private revenues available for financing the delivery of care related to Alzheimer's disease and related dementias.

Families bear most of the expense related to dementia, including some of the costs of diagnosis, almost half of the costs of long-term care institutionalization, and nearly all of the costs of in-home and community-based care. The financial burden increases and intensifies the emotional, psychological, and physical burden of caregiving. Patients and families have finite resources available to cover the costs of care over many years. Similarly, federal and State government, while providing some funding for care of dementia patients and their families, are currently not providing adequate coverage for the range of services necessary for combating this disease. At present, there is a lack of innovative revenue generating mechanisms to pay for, or assist families to pay for, the entire range of care for dementia patients.

Financing Issue #8: There are limited sources of public and private revenues available for financing research related to Alzheimer's disease and related dementias.

Public and private funds available for supporting basic and applied research in the area of dementia are inadequate. Federal and private sources of funding, while growing, are not nearly sufficient to conduct the extensive number of biomedical, clinical, and health service research studies needed in the fight against Alzheimer's disease and related dementias. At present, there is a lack of innovative revenue generating mechanisms to pay for critical research priorities.

Financing Issue #9: At present, there is no integrated or standardized health and social service financing mechanism to pay for the care of patients with Alzheimer's disease or related dementias and their families.

Medicare, Medicaid, Title XX of the Social Security Act, The Older Americans Act, and Veterans Assistance programs provide the vast majority of financial support for patients with dementia or other long-term or chronic impairments. In general, there has been no integrated financing mechanism for these programs; as a result, service delivery is fragmented. In California, this is particularly evident for services provided through Medicare, Medi-Cal, In-Home Supportive Services (IHSS), mental health Short-Doyle, and programs funded under The Older Americans Act. While capitated systems--such as Health Maintenance Organizations (HMOs), Medicare HMOs, and Social Health Maintenance Organizations (S/HMOs)--have recently expanded the availability of integrated financing mechanisms for long-term care services, there is still a dearth of coordinated, comprehensive financing for long-term care, particularly for dementia patients.

Financing Issue #10: Comprehensive actuarial data on the prevalence of Alzheimer's disease and related dementias and data on the cost of care for dementia patients are not available.

Information available on the number of individuals with dementia is very limited and, even when available, generally not comprehensive and often not reliable. Consequently, the preliminary studies estimating the costs of formal care (i.e., institutional and community-based care) and informal care (i.e., provided by families) are equally unreliable. Better data would make it possible to estimate more precisely the prevalence of dementia by degree of impairment, the sources and extent of informal support, utilization and cost of health and long-term care services, and distribution of expenditures by type of patient, type of service, and source of financing. Lack of adequate data and confusion over unsupported and conflicting data contribute to the difficulty of determining the potential budgetary impact of policy initiatives to provide assistance to Alzheimer's disease patients and their families.

Recommendations

A . The Governor and Legislature should immediately approve expanded Medi-Cal coverage for services required by dementia patients and their families. Expanded coverage should specifically include diagnostic services; respite care; Alzheimer's disease day care; specialized residential facility, intermediate care facility, and skilled nursing facility care; hospice care; and autopsies.

B . The State should seek from the federal Department of Health and Human Services a waiver from existing Medicaid regulations for the purpose of obtaining federal financial participation in funding in-home and community-based services to Medi-Cal eligible individuals with Alzheimer's disease or related dementias who would have to receive inpatient or nursing home care but for the provision of in-home and community-based services. The State should submit the waiver request no later than January 1, 1988.

C . The Governor and Legislature should direct the California Department of Insurance to work with representatives of the health insurance industry to (1) write a legislative proposal designed to give the industry adequate incentives to develop loss reserves sufficient to stimulate the development and aggressive marketing of long-term care insurance plans, and (2) write a legislative proposal designed to develop a model long-term care insurance program which specifically covers dementia patients. Such plans must be responsive to the care needs of dementia patients. Specifically, these programs must cover skilled and basic personal care including in-home, community-based, and institutional long-term care services not covered by Medicare and Medi-Cal, including respite care. The proposed concept should address the findings of the State Long-Term Care Insurance Task Force. Options which can be pursued include, but are not limited to, the following:

- A Comprehensive Health Insurance Plan made available through the State of California to all State residents suffering from disabilities or chronic diseases, such as dementia. This plan would provide a State-backed insurance pool tailored to provide affordable insurance. Those who enter the program would pay premiums higher than those offered by regular group medical policies, but would have a fixed liability. Premiums paid into the pool would cover most of the costs of the program, but the State would be responsible for covering cost overruns.
- A voluntary, supplementary Catastrophic Health Insurance Program made available through the State of California to all State residents to meet the threat of catastrophic illness or injury, including dementia. This program would not be a State-backed insurance program, but would utilize a State Insurer that would serve as a risk management contractor to the State. Those who enter the program would pay premiums only according to chronological age and, in return, would have a fixed liability.

D. The Governor and Legislature should amend California law to provide tax incentives to families to continue caring for dementia patients. These amendments should include, but not be limited to, the following elements or considerations:

- Tax credits or exemptions should be extended to families caring for dependent dementia patients (similar to current law regarding provisions for care of dependents who are blind).
- Tax deductions should be extended to the spouse or adult child of a dementia patient for medical expenses, financial payments toward safety equipment (such as special shower chairs and safety bars), prescription drugs, and home health, personal, and skilled nursing facility care.
- The definition of medical expenses should be expanded to specify items of daily utility which are necessary for the care of dementia patients, although they do not fall under definitions of strict medical necessity (e.g., gates and safety latches).
- A tax credit should be established explicitly for out-of-pocket expenses related to the care of a dependent afflicted with a chronic debilitating disease, such as Alzheimer's disease. This credit should specify a ceiling for the amount that can be deductible.
- Certain criteria should be set for allowing tax incentives, such as limiting the incentive to individuals who contribute to in-home or community-based care for persons afflicted with a chronic debilitating disease, such as Alzheimer's disease.

Any action to reform State tax codes should include a provision to memorialize the federal government and Congress to make similar reforms at the federal level.

E. The Governor and Legislature should direct the California Department of Insurance to write a legislative proposal designed to develop a model tax incentive program which encourages individuals to assume a portion of the responsibility for paying for long-term care and specifically covers dementia. This proposal should be submitted to the Governor and Legislature by July 1, 1988, and should include, but not be limited to, the following options or considerations:

- Eliminate taxation of funds withdrawn from Individual Retirement Accounts (IRAs) when such withdrawals are made for the purpose of purchasing long-term care services in the home, in community-based programs, or in intermediate care or skilled nursing facilities.
- Allow personal investments in "individual medical accounts" (IMAs) to be established solely to enable individuals to pay specified health care costs (which include in-home and community-based long-term care). Deposits (up to an annual maximum) would be excluded from gross income and exempt from income and estate taxes at the time of withdrawal, provided the funds are used to pay health care costs.

Any action to reform State tax codes should include a provision to memorialize the federal government and Congress to make similar reforms at the federal level.

F. The Secretary of Health and Welfare should direct staff from the Departments of Health Services, Social Services, Aging, Mental Health, and the Office of Statewide Health Planning and Development to write a legislative proposal designed to implement rate differentials or supplemental reimbursement for specialized care based on appropriate levels of quality care for dementia patients in in-home and community-based programs, as well as institutional settings. This proposal should be prepared and submitted to the Governor and Legislature by no later than July 1, 1988.

G. The Secretary of Health and Welfare should identify and eliminate the barriers in existing law and regulations to the awarding of appropriate disability and pension benefits to individuals afflicted with Alzheimer's disease and related dementias. The Secretary of Health and Welfare should report these findings and recommendations for eliminating or mitigating these barriers to the Governor and Legislature by no later than July 1, 1988.

H. The Governor and Legislature should expand revenue generating mechanisms for the support of care for dementia patients and their families, as well as for supporting Alzheimer's disease research. These mechanisms could include, but are not limited to, the following options:

- Shared State Lottery proceeds for the provision of care to patients with Alzheimer's disease or related dementias and their families.
- A health insurance surcharge of 0.1 percent (one-tenth of 1 percent) to be collected on all health insurance premiums. The full surcharge would be paid by each insured--not employers or insurance carriers. Employers who pay for their employees' health insurance would be authorized to deduct the surcharge from each employee's wages (25 cents a month, for example, on a monthly premium of \$250.00) to send to insurance carriers who would then be responsible for making a monthly payment of this surcharge to the State. Monies collected as a surcharge on health insurance would be deposited into a "California Long-Term Care Fund" to be established in the State Treasury and to be continuously appropriated without regard to fiscal year and administered by the Health and Welfare Agency. Expenditures from the "California Long-Term Care Fund" would be made according to priorities and criteria determined by the Health and Welfare Agency. These should include but not be limited to conservatorship services for indigent dementia patients, respite care for dementia patients and their families, and research investigations as specified in the Research section of this report.
- California taxpayers should be given the opportunity to contribute to State funds for research in Alzheimer's disease and related dementia research through the mechanism of adding a line to the "Voluntary Contributions" section on the State tax form. These funds should be directed to the Health and Welfare Agency research fund and be in addition to (and not replacing) funds allocated through the State General Fund.

I. The Governor and Legislature should improve the availability of public and private financing mechanisms for care for dementia patients and their families and further seek a means to integrate financing streams. These mechanisms should be submitted as a proposal from the Secretary of Health and Welfare to the Governor and Legislature by July 1, 1988, and should include but not be limited to the following options:

- The Governor and Legislature should memorialize the federal government and Congress to expand Medicare coverage for long-term care, including institutional, community-based, and personal care (and specifically respite care). This may best be accomplished through the establishment of a "Medicare Part C".
- The Secretary of Health and Welfare should develop a proposal to integrate financing for long-term care services provided through Medicare, Medi-Cal, In-Home Supportive Services (IHSS), mental health Short-Doyle funds, and The Older Americans Act funds, particularly for dementia patients and their families.
- The Secretary of Health and Welfare should develop a proposal to encourage capitated health care delivery systems in California--such as Health Maintenance Organizations (HMOs), Medicare HMOs, and Social/Health Maintenance Organizations (S/HMOs)--to expand their coverage of long-term care, particularly to dementia patients and their families.

J. The Secretary of Health and Welfare should collect, analyze, and summarize data and information from appropriate studies of long-term care financing problems and options and submit a summary of these data to the Governor and Legislature by July 1, 1988. This report should also include recommendations for increasing the availability of actuarial data on the incidence of Alzheimer's disease and related dementias as well as accurate and comprehensive cost data on long-term care services provided to dementia patients at home by community-based programs, and in residential, intermediate care, and skilled nursing facilities. The State should also support research into the costs of care for Alzheimer's disease and related dementias, including standardization of measurements of the costs of care.

IV. LEGAL ISSUES

The mental deterioration caused by Alzheimer's disease and related dementias creates legal ambiguity regarding who should make decisions for patients who are mentally incompetent. Many of the legal issues specific to dementia patients have evolved out of the conflict of the need for families to protect their assets (especially in cases of shared property or joint occupancy of a home by patient and primary caregiver) versus the fundamental right of the individual to control his or her own property and to manage his or her own affairs, including giving or withholding consent for any bodily invasions such as medical treatment. Dementia patients reach a point where they can no longer care for their own needs in a reliable fashion or make meaningful decisions regarding their health care, financial affairs, or living situations.

In Alzheimer's disease and related dementias, irreversible deterioration of mental capacity often progresses slowly and the patient may not acknowledge the symptoms even after his or her capacity to make reasonable decisions has become questionable. Indeed, an incident evolving out of a breakdown in judgment may be the initial trigger for clinical investigation of the disease and ultimate diagnosis of Alzheimer's disease.

Determining competence in an Alzheimer's disease patient is complicated by the fact that, especially in the early stages of the disease, the dementia patient is able to make some decisions but not others, or may be intermittently competent. Furthermore, Alzheimer's disease patients may be suspicious, paranoid, and argumentative as part of the normal course of their disease. In this state of mind, patients may be technically competent, but their judgment is surely impaired. To the extent they continue to make their own financial and health care decisions, dementia patients may impose great emotional and financial burdens on their families.

Legal Issue #1: Existing law in California is inadequate to meet the unique needs of dementia patients for surrogate decision makers.

The dominant legal concern for dementia patients and their families has to do with surrogate decision making. Having been designed to protect primarily the mentally ill or medically comatose, existing law fails to accommodate the unique circumstances imposed by progressive and irreversible dementia.

The legal mechanisms available for surrogate decision making are: (1) durable power of attorney (DPA), (2) durable power of attorney for health care (DPAHC), (3) probate conservatorship, and (4) Lanterman-Petris-Short (LPS) conservatorship.

1. Durable Power of Attorney (DPA) is a written document giving someone other than the "Principal" authority to handle the Principal's financial decisions. The Principal must be fully competent at the time the DPA is written. The DPA is valid without time limit until the Principal either revokes the DPA or dies. The subsequent incapacity of the Principal --which must be attested to by a physician--does not affect DPA powers. Financial decisions made by an individual given DPA by the Principal are binding on the Principal and his or her successors.
2. Durable Power of Attorney for Health Care (DPAHC) is also a written document which must be signed by the Principal while he or she still has the capacity to make decisions. The DPAHC gives someone other than the Principal authority to make medical treatment and health care decisions on behalf of the Principal for up to a maximum of seven years after the document is signed. If a condition has been diagnosed as terminal, an individual with DPAHC is empowered to authorize attending physicians to remove artificial life supports. Powers of DPAHC do not include commitment or placement of the Principal in a locked or mental health facility.
3. Probate Conservatorship refers to a situation wherein the Principal presently lacks capacity to assign to anyone else the authority to make financial or health care decisions on his or her behalf and also did not previously designate power of attorney to another party. In such a case, the court will appoint a conservator (who may be a relative) to oversee the Principal's assets subject to court review.
4. Lanterman-Petris-Short (LPS) Conservatorship includes the power to authorize involuntary inpatient or outpatient mental health treatment. Inpatient treatment may include involuntary placement in a locked facility or secure environment. The LPS Conservator can be the Principal's spouse, child, or any other individual willing to assume this responsibility. An LPS Conservatorship is valid for one year and initially requires:
 - a psychiatric evaluation;
 - contact with the local department of mental health;
 - a social worker interview with the proposed LPS Conservatee;
 - a petition filed with the court by the local department of health; and
 - a court hearing, which the proposed LPS Conservatee must attend unless a medical declaration states that "serious and immediate physiological damage" would result.

Annual renewal of an LPS Conservatorship requires :

- written medical opinions from two physicians or psychologists that involuntary mental health treatment is still appropriate;
- a petition filed with the court by the LPS Conservator; and
- a court hearing, which the LPS Conservatee must attend unless a court-appointed attorney has visited the Conservatee and stipulated that the Conservatee's condition has not changed.

The characteristics of Alzheimer's disease patients that make currently available legal mechanisms for surrogate decision making inadequate are as follows:

1. Due to the gradual onset of the disease, the dementia of a person stricken with Alzheimer's disease often progresses to the point where a patient lacks the capacity to make financial or health care decisions for himself or herself before anyone considers the need for surrogate decision making. Often the medical crisis triggering diagnosis and treatment is the first instance of contact between the dementia patient and existing systems for health care or legal services. At that point, patients often lack the capacity to sign a durable power of attorney or durable power of attorney for health care.

2. The seven-year limitation on validity of the durable power of attorney for health care is not realistic in the specific case of dementia patients. Progressive mental and physical deterioration in Alzheimer's disease patients can exceed 20 years and typically exceeds the current limit of seven years.

3. "Wandering" by dementia patients is common and makes providing care for them in a secure environment essential. Existing treatment programs do not constitute a continuum of care specific to Alzheimer's disease and related dementia patients. Consequently, facilities currently willing to serve these individuals are either technically "open" facilities (such as nursing homes)--which employ alternate restraints such as tying, geri-chairs, or chemical restraints--or locked facilities which, in the California system, typically are psychiatric facilities. Neither of these options is truly an appropriate environment for Alzheimer's disease and related dementia patients but, even if facilities designed to provide care specifically for dementia patients were available, there is currently no surrogate decision making mechanism available to permit involuntary placement of dementia patients into such facilities when needed.

4. Alzheimer's disease and related dementia patients do not recover lost mental capacity. The mentally ill often recover competency and, thus, it makes sense to safeguard their rights of due process on an annual basis. Provided medical assurances indicate the dementia is irreversible, however, the duration limits and reversal requirements in existing law are not relevant to the condition of Alzheimer's disease patients and serve only to increase hardships on caregivers. Producing such medical assurances can be costly due to having to determine diagnosis by a process of elimination. This process includes complete medical histories, complete functional assessments, and a battery of tests including a physical examination, neurological and psychiatric evaluations, mental status examination and psychometric tests, and appropriate laboratory tests. If testing